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ADD Program Update

Administration on Developmental Disabilities

Administration for Children and Families • U.S. Department of Health and Human Services

Commissioner's Message

Regional Conference Calls

Late this spring two conferences were held in the Washington, DC Metro area: the Protection and Advocacy/CAP conference and the Councils' Technical Assistance Institute. Perhaps one of the greatest outcomes of this conference was the realization that ADD needed to improve communication between the grantees, regional offices, and ADD headquarters.

In that spirit, I proposed a series of conference calls organized by program and region with the grantees, regional staff, and relevant headquarters personnel participating. Participants are invited to submit agenda items in advance for discussion in the meetings. SCDD regional conference calls are scheduled on Tuesdays, UCEDDs conferences calls are being conducted on Wednesdays, and P&As are meeting on Thursdays, all at 2 p.m. Eastern. Meeting participants must RSVP so that we may provide the dial-in code, and so that we can be certain to reserve enough in-bound lines for the call. Reservations and agenda items must be received no later than the Friday preceding the call, 5 pm Eastern. Agenda items can be submitted to your regional contact person. Once all agenda items have been collected an agenda will be distributed to all those who have indicated that they will participate in the call. Following each meeting, minutes or summaries will be made available to all program grantees in the region.

We began the regional conference call series with major topics of conversation that included MTARS scheduling and revisions and the status and potential impact of the Help America Vote Act. Other topics covered were: self-advocate internships and how ADD can best take advantage of presently available Federal intern positions; technical assistance needs; and the challenge of simplifying the PPR process. We also discussed the desired outcomes for the regional conference calls and strategies for effective communication. I am pleased with the initial feedback from these conference calls, and with the willingness exhibited to voice concerns and ideas in this new format. I am also looking forward to suggestions for our long-term communication strategies once we complete this 15-call cycle.

Effective communication between the administration and the grantees is critical to the mission of ADD. It is essential that our grantees know that the Federal staff is accessible to them, and that starts with my office. Please view these conference calls as an opportunity to voice your concerns. As always, staff, grantees, consumers and self-advocates are also welcome to send e-mail to me and my senior staff conveying their concerns, successes, or suggestions. My e-mail address is PMorrissey@acf.hhs.gov, Debbie Powell is DPowell@acf.hhs.gov, and Faith McCormick is FMcCormick@acf.hhs.gov.

For your convenience, the following is a listing of the appropriate regional contacts:

Region	SCDD and P&A ADD Contacts
Region I	Alonzo Stewart
Region II	Jackie Ezzell
Region III	Gretchen Menn
Region IV	Jocelin Gridley
Region V	Carla Brown
Region VI	Isadora Wills
Region VII	Mary Beth Greene
Region VIII	Isadora Wills
Region IX	Shirley Redmond
Region X	Gretchen Menn

Region	UCEDD ADD Contact
Region I	Ophelia McLain
Region II	Dianne Winford
Region III	Ophelia McLain
Region IV	Valerie Reese
Region V	April Myers
Region VI	Diann Winford
Region VII	Joan Rucker
Region VIII	Joan Rucker
Region IX	Sharon Delany
Region X	Sharon Delaney

Program Progress

Protection and Advocacy Agencies

Making a Difference

Chicago Equip for Equality, Illinois' P&A, has won a significant victory. EFE filed a wrongful death suit in October 2000 on behalf of the estate of Jennifer Klimek. Klimek, 36, had Prader-Willi Syndrome, a condition that caused her to have intellectual disabilities, as well as an insatiable appetite. She died in the custody of the Glenkirk Housing Association, who failed to supply her with adequate supervision. Klimek's death was the result of ingesting a lethal amount of alcohol. The facility and five individuals were named in the suit. A settlement was reached among the parties for an unspecified sum. Glenkirk also agreed to revise staff training practices, as well as some other policies and procedures. EFE staff were pleased with the outcome because it helped to raise awareness at the Glenkirk community, which will hopefully improve the quality of care for other Glenkirk residents.

P&A 26th Annual Conference

The conference was held May 28-June 1, 2003 at the Renaissance Hotel in Washington, DC. This conference continues to grow and be a favorite of P&A staff, Governing Boards/Advisory Councils members, state and federal agencies, other advocacy groups and the general public. Over 600 people attended the conference and gave positive feedback. It appeared to be an overwhelming success.

In addition to the vast array of workshops and institutes, a governance institute was held as a half-day session after the P&A Orientation for new staff and governing board/advisory council members. The conference evaluations received indicated that this institute needs to be a regular part of this conference and the agenda expanded to include an in-depth presentation on specific/critical issues. ADD thanks the P&A executive directors for recognizing this need and sending their governing leadership to this conference.

P&A Fiscal Management Training

Preparations are well underway for the Fiscal Management Training to be held August 14-16, 2003 at the Wyndham Washington Hotel. ADD's Training and Technical Assistance contractor, NAPAS, received your comments and used them to develop the sessions. For the first time, a new fiscal managers' orientation will occur on Wednesday, August 13th, from 2:00 – 5:00 pm. We encourage you to bring your questions because the relevant experts will be on hand to answer them. We look forward to meeting you.

Examples of Best Practices in the P&A System

Community Monitoring of Ombudsman Program

The New Mexico P&A runs the Community Ombudsman program. This program is funded by the state Developmental Disabilities Council. The program serves clients of the developmental disabilities system in New Mexico as well as their family members to resolve problems in the delivery of services in the community and intermediate care facilities. Ombudsman staff provides information, advice and self-help materials. Staff also negotiates for service plan improvement or for a commitment to deliver needed services in the community. Direct assistance to consumers is available to resolve grievances, and referrals to legal assistance are made when necessary.

Recruiting and Training Community Based Direct Care Workers

The Colorado P&A was a sponsor of a state-wide coalition bringing together many disability advocacy groups in the state to identify ways to recruit and train competent community services staff and to identify successful methods for serving high risk individuals. The coalition meeting was facilitated by the Executive Director of the P&A. As a result of the coalition, the P&A reiterated its commitment to help family members plan the thoughtful coordinated downsizing of Colorado hospitals for individuals with disabilities over three years, making alternative services available in the community. An example of the Colorado P&A's ongoing commitment to ensuring community services is their success in obtaining a court order prohibiting the state from discriminating against people with developmental disabilities by providing them with less access to community-based services, like respite care, personal assistance and homemaking, than the elderly and persons with physical disabilities.

Ensuring appropriate Medicaid Services for Adults

The New York P&A developed an "aging out" program. The program addresses the problem of individuals who, upon turning 21, lose youth-based funding for community services and supports and fail to receive adequate information from the state on how to get adult funded community services. The program establishes task forces comprised of people with disabilities and disability advocates who assist in informing parents about the services available for youth approaching age 21 to help them to make a smooth transition to services for adults in the community.

Educating Consumers about Advance Directives

The Florida P&A is in the early stages of establishing advance directives pilot projects, in four geographically diverse counties. Each project will involve:

- ✦ a stakeholder advisory group comprised of consumers, local providers of community mental health services, representatives of state mental health programs, drop-in center staff, mental health advocacy and consumer run organizations, the P&A and legal aide representatives.
- ✦ the training of 10-15 individuals from that advisory group about state law concerning advance directives for mental health.
- ✦ the trainees identifying three consumers who are interested in and likely to need an advance directive in the future and who will accompany them to a day-long training on developing a directive.
- ✦ the consumers providing copies of their directive to their chosen proxy, and anyone else they select. If in the future their directive is not honored, the P&A will open a case to determine why and seek remedies.
- ✦ data collection and evaluation by an independent outside agency after one year to identify successes and problems with the current state law and the training.

It is hoped that individuals who are trained will continue to train others, and that the data collected by the project will provide incentive for state providers and others to promote advance directives for mental health.

HAVA Activities

Over 30 P&As have a seat on their state's HAVA Planning Committee. Nearly all the P&As have been involved in some way in their state's HAVA planning process.

A few P&As, including North Carolina, Montana and Alabama have been asked by their state chief election officials to participate in the drafting of the state plan for how to use the funding under the Election Assistance for Individuals with Disabilities provision under HAVA. All eligible P&As have submitted applications for the HAVA P&A grant funds and the awards will be made shortly.

Americans with Disabilities Act (ADA)

Training

The Virginia P&A provided training to the state agency charged with licensing day care facilities and is collaborating with the agency to provide training to day care operators throughout the state. Additionally, the P&A is taking part in an ongoing review of the state licensing regulations for these facilities to ensure compliance with the ADA.

State Councils on Developmental Disabilities

TA Institute

The ADD Technical Assistance Institute for SCDDs was held June 2-3, 2003. A full summary will be available in the next issue of ADD Update. The following are examples of the success stories presented at the closing session of the TA Institute.

New York

Anna Lobosco, NY DD Council

The New York Council convened a group of consumers of personal assistance services whose advocacy led to the establishment of a Consumer-Directed Personal Assistance Services (CDPAS) Program within the NYS Department of Health and a mandate for offering this option to those individuals needing personal assistance services. The bill was passed by the State legislature and enacted by Governor Pataki.

Grant dollars provided pre-start up guidance to agencies in each county as they built their CDPAS programs, amended the Medicaid billing system, assisted consumers to learn how to manage their own personal assistance services (hiring, firing, training, etc.), and established a statewide CDPAS vendors association. In a relatively short amount of time, all NYS counties had established CDPAS programs and the model is being touted for its integral importance in responding to the needs of individuals seeking to move from institutional to community settings in response to the Olmstead decision.

Maryland

Brian Cox, Executive Director, Maryland DD Council

The goal of Family NETWorks, a family-centered and directed project of the Maryland DD Council is to foster family empowerment and self-determination; outreach to underserved families; and impact systemic policy issues. The project exceeded its goals over a three-year period through an interactive and family friendly website, innovative grants, and the work of a Policy Panel. Family NETWorks continues to grow and build on this foundation.

- ✦ Website and Listserve: Over 1 million hits and 36,000 users, allowing families and others to share ideas, discover resources, and connect.
- ✦ Grants: 8 diverse mini-grants and 19 support grants throughout the state that developed innovative collaborations; outreached and informed underserved communities; and established, strengthened and empowered local parent-led and self-advocate-led groups. The website and grantees reached, among others, families whose child was recently diagnosed, military families;

Latino, Korean & Orthodox Jewish families; & families in urban empowerment zones and rural areas of the state.

- ✦ Policy: A policy panel analyzed and impacted systemic family support issues as diverse as EPSDT, Maryland's Medicaid waiver, and respite care.
- ✦ Family NETWorks is an in-house project established through an ADD family support grant. The project will continue through other Council funds. The majority of project staff are parents of children with developmental disabilities. More details at www.family-networks.org, click on "About the Project."

Wisconsin

Jennifer Ondrejka, Executive Director, Wisconsin DD Council

Movin' Out: Parents Mobilize Statewide Home Ownership for People with Disabilities

In the winter of '92 six parents met in a basement conference room in Madison, Wisconsin. The topic of discussion was the future of their teen-age and young adult sons and daughters. Their children were graduating from high school special education programs. They had high hopes for the adult roles, responsibilities, and opportunities awaiting their children. But they were concerned that needed support would not be available. As their children became too old for school, the parents learned that waiting lists for adult services were likely to stall their dreams.

The parents realized they could not simply hand over responsibility for their children's support to the human services system. The parents decided to invest their time, energy, and resources over the long haul. They embarked on a volunteer research project to explore what it would take to secure integrated housing matched with reliable support. The parents learned from talking to organizations inside and outside the developmental disabilities service system. They factored in their own dreams and plans for their children. They decided to establish a non-profit corporation to carry out the vision taking shape about integrated housing. They named the new agency Movin' Out.

Their advocacy and vision yielded an initial investment and continuing support from the Wisconsin Council on Developmental Disabilities. The county earmarked service funding for families to experiment with innovative arrangements. Movin' Out secured funding from public housing authorities and financial institutions allowing the new agency to distribute down payment assistance funds and offer housing counseling. With this foundation in place, the hardy group of parent advocates volunteered as board members and unpaid staff. Soon the agency had the means to hire staff. Here is a partial list of accomplishments from the first parent meeting 10 years ago to the birth and growth of a statewide housing organization specializing in home ownership for people with developmental disabilities and their families.

- ✦ Down payment assistance: Movin' Out has generated and distributed almost \$4 million in down payment assistance to over 400 households.
- ✦ Information, training, and housing counseling has been provided to hundreds of prospective home owners with disabilities and thousands of family members and advocates throughout Wisconsin.

- ✦ Movin' Out established itself as a respected and responsible housing partner with financial institutions, federal, state and local public housing authorities, with the Federal Home Loan Bank, with Realtors, with architects, with developers, and with municipalities.
- ✦ Movin' Out was a partner in developing Coachyard Square in Madison: a 21-unit condominium that is a living example of integrated housing.
- ✦ Movin' Out is a partner in developing Uplands, a new, intentional, integrated community in Sun Prairie—142 homes on 30 acres—some rental, some owner occupied.

Nevada

Ken Vogel, Executive Director, Nevada DD Council

The Nevada Council on DD Project -Consumer Leadership Development Program – is a collaboration with State Assistive Technology and Independent Living programs. Funding has supported people with disabilities and family members to participate in a wide variety of workshops and training in leadership, self-advocacy and policymaking activities. The project has also facilitated discussions with nationally recognized speakers on topics such as Olmstead, ADA, Health Care, housing, etc. to develop the Strategic Plan which has been designated as Nevada's Olmstead Plan. Legislation is about to be passed to create a Legislative Committee on Disabilities to help the disability coalition oversee the implementation of the Strategic Plan over the next 10 years.

The Strategic Plan has paved the way for major systemic changes in the service delivery system for people with disabilities in Nevada including an Office of Disability Services at the Director's level of the Department of Human Resources. This office will help "defragment" the system as it currently exists by providing a single point of entry for information about services for people with disabilities throughout the state. This office will embrace the concept of "No Wrong Door" in providing people with disabilities and their families easier access to and information about services that exist statewide. The Consumer Leadership Development Program has also provided the Nevada Partners in Policymaking program with funds to assist participants with travel expenses to attend the classes. One Partners graduate has become a DD Council member and others have joined other disability-related councils and boards around the state. Still others have successfully used their training to testify before the Nevada Legislature.

University Centers for Excellence in Developmental Disabilities Education, Research and Services

Progress through Research

Researchers at Kennedy Krieger in Maryland are the first in the country to scientifically study the effectiveness of a nontraditional therapy, called "energy therapy," on children with developmental disabilities. Energy therapy is a form of complementary or alternative medicine that involves the use of the body's electromagnetic system. Through the hands of a healer, this continuous field that surrounds the body is balanced, by light touch, to aid in healing. Like many alternative therapies, its efficacy is mostly anecdotal; until now, it has not been studied in controlled, scientific trials.

Previously conducted pilot studies at Kennedy Krieger have shown that energy therapy significantly calms and relaxes some children, allowing them to be more receptive to traditional therapies and in some cases enhancing the ability to more easily provide range-of-motion therapy. Families at

Kennedy Krieger can opt to participate in alternative therapy as a complement to traditional therapies. For example, a child with cerebral palsy who has painful stiffening of the muscles in his or her limbs may experience noticeable reduction of muscle tension following an energy therapy treatment, which makes physical therapy more tolerable and effective.

Continuous Improvement in Long Term Care

Building on and adding to a previous distance education Long Term Care Certificate project and previous experiences in allied health education and training, The University of Maine Center for Community Inclusion, in collaboration with Husson College, The University of Maine School of Social Work and College of Education and Human Development, and the Maine Department of Education, is developing, evaluating, and disseminating an expanded and innovative continuation. The Modular Long Term Care Project is updating existing knowledge, skills, and values and reorganizing content into educational modules for multiple and widespread learning across three student groups: middle and high school students, pre-service allied health professional students, and continuing education allied health practitioner students. Specific attention is directed to recruitment of disadvantaged students into allied health careers and to education of pre-service and current practitioners to address and remediate health disparities experienced by rural residents including ethnic minorities and individuals with disabilities.

Education

The Kentucky Peer Service Learning Project (University of Kentucky) originally began working with five Kentucky high schools under the umbrella of an education project. The project conducted a two-day workshop for its five schools. The training focused on developing inclusive service learning activities and promoting self-determination for students with significant disabilities. In March 2003, the project, in collaboration with teachers and peer tutors from its five pilot sites, conducted a three-hour workshop at the Kentucky Spring Council for Exceptional Children conference.

Program Performance

Electronic Data System (EDS)

Highlights from FY 2002 Program Performance Reports

Housing

State Council on Developmental Disabilities

National Aggregate:

- 🚩 29 Councils reported that 5,921 (a 47 % increase from FY 2001 data) individuals have homes of their choice through council efforts.
- 🚩 16 Councils reported that 272 people moved from congregate settings to homes in the community.

Florida

The CASA Program funds property management staff for a service provider who purchases property and rents to income-eligible individuals with developmental disabilities. The acronym CASA stands for homes that are: Convenient, Affordable, Safe and Attractive. During the contract year, four homes were purchased for a total of 11 that are rented to 23 adults and one child. An independent evaluation of this program studied, and validated, the current Florida administrative rule that prevents disability service providers from leasing their own properties to the individuals they serve and the challenges created when the landlord is also one of several potential service providers. The final report concluded that the issues of choice and control continue to be of concern in the current design but supported continuation of the project as an opportunity to reconsider ways to realize affordable housing while at the same time respecting the need for choice and control by Florida's citizens with disabilities. A third year of funding will enable creation of a separate housing organization.

Mississippi

Twenty people with D/DD became home owners during the reporting period. In July 2002 The MS Home of your Own (HOYO) project received a state award. Governor Ronnie Musgrove presented HOYO with the 2002 Governor's Community of Excellence Award for Best Homebuyer Assistance Project. The award was presented to Ms Vicki Killingworth and Mr. Royal Walker, both Council members and staff in the Center of Excellence. There are many success stories that can be told about 60 people becoming home owners during the past three years. To site one recent newspaper article, Ms Karen Gill and her son who is a wheelchair user with significant Developmental Disabilities tells about their home ownership dream coming true. They have lived in an apartment for 17 years and often talked about having a house and a yard. She told about the excitement that Russ, her son with a disability, now experiences by having his first dog and a yard. Ms Gill said the home buyer process took about 18 months from start to finish, but now that they have their new home it was worth the wait and paperwork.

State Protection and Advocacy System:

National Aggregate:

- 45 P&As reported 550 people with developmental disabilities secured or maintained accessible housing due to P&A interventions.

District of Columbia

Under the Consent Order, DCHA will provide ramps to public housing tenants who use wheelchairs and request ramps as a reasonable accommodation to enable them to get into and out of their homes. These ramps and other reasonable accommodations will not affect DCHAs obligation to offer to transfer tenants to UFAS Accessible Units upon request and in accordance with DCHAs policy. DCHA will offer partially accessible units (such as units with ramps) first to tenants with mobility impairments who need the accessible features, and next to applicants with Mobility Impairments who reach the top of the public housing waiting list and qualify for the public housing selection pool.

New Hampshire

FP had been notified that she would need to move immediately to a different home against her wishes. The provider had forced her to sign papers agreeing to the move. The home in which FP lived was to be decertified - not because of health or safety issues, but because the provider agency said it was out

of funds. There was personal animosity between the housing provider agency and the home provider. FP felt pulled in every direction as she was being told by the housing provider that she had to move and that she was only saying she wanted to stay to please her provider. She began to eat less and was unable to go to work. The P&A advocate reminded all involved that the state required client choice and that it should be respected. Interactions between FP and her provider became more complicated resulted in FP making her own decision to move. She is happy in her new home and did not need any continued assistance from the P&A.

Upcoming Events & Announcements

New Home for AUCD

The Association of University Centers on Disability (AUCD) has moved into their new office. They are now located at 1010 Wayne Avenue, Suite 920, Silver Spring, Maryland, 20910. Their offices numbers remain unchanged; phone 301-588-8252 and fax 301-588-2842.

2003 AUCD Annual Meeting Update

AUCD has received an enthusiastic response to its Call for Participation for the AUCD 2003 Annual Meeting and Conference scheduled for November 9-12 at the Hyatt Regency in Bethesda, MD. The theme for the meeting, "Strength in Diversity," allows for many different types of presentations which reflect cultural, ethnic, disability, age and discipline diversity as well as the partners involved in our network. All network members are encouraged to submit their proposals for presentations, roundtables and poster sessions.

First Annual NACDD Meeting

The National Association of Councils on Developmental Disabilities will hold their first annual conference on November 9-11, 2003 at the Sheraton City Ctr, Salt Lake City, Utah. The theme of the conference is "Tending the Flame, Passing the Torch." Keep coming back to the NACDD website for updates: <http://www.naddc.org/>.

ADDED Resources

The PNS program announcement for "Family Support 360" FY 2003 is available on the ADD website at <http://www.acf.dhhs.gov/programs/add/PNS2003.htm>